Missouri Department of Elementary and Secondary Education Division of Special Education

Report on First Steps Children Identified through the Newborn Hearing Screening Program

September 2004

Under the Newborn Hearing Screening law, Section 191.931 RSMo, the Missouri Department of Elementary and Secondary Education shall "monitor the delivery of early intervention services to those infants identified by the newborn hearing screening program and report annually to the department of health."

This report will be divided into four sections, structured as follows¹:

- 1. Analysis of the number of children enrolled in First Steps who were identified through the aforementioned newborn hearing screening program during calendar year 2003.
- 2. Early intervention services given to these children under their Individualized Family Services Plans (IFSP).
- 3. Amplification or other assistive technologies children are receiving under their IFSP to address their hearing loss.
- 4. A look at the children identified in 2002 and their progress within the First Steps program.

Personally identifiable information is left out of this report, as inclusion of such without parental consent would violate protections of the Family Educational Rights and Privacy Act (FERPA), incorporated by reference in the Individuals with Disabilities Education Act.

Children Identified by the Newborn Hearing Screening program and enrolled in the First Steps program

2003 Newborn Hearing Screening List	
156 total children	
73 in First Steps Database	
62 found eligible	
4 inactivated	
	3 withdrawn by parent/guardian
	1 deceased
58 still active	
	52 active IFSPs
	6 Initial IFSPs expired; awaiting
	next IFSP

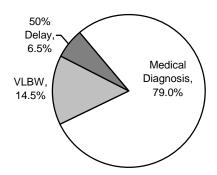
From the Department of Health and Senior Services' (DHSS) list of 156 children born in the 2003 calendar year and identified through the Newborn Hearing Screening (NHS), there were 73 children in the First Steps database as of August 2004. Sixtytwo of those 73 had been deemed eligible for First Steps services through one of Missouri First Steps' three main eligibility criteria—50% delay in one developmental domain, medical diagnosis, or very low birth weight, 61 had received services through an

Individualized Family Services Plan (IFSP), and 58 were listed as active in the system as of August 22, 2004.

¹ Child outcome data was included in the September 2003 Newborn Hearing Screening report. Outcome data is currently not reliable or readily available and will not be included in this report. Within the next year, DESE will have implemented a web-based First Steps database with much more detailed information available for collection and analysis. Data on the status of outcomes listed on the IFSP will then be available and will be included in next year's report.

Forty-nine of the 62 eligible children (79.0%) were deemed eligible by means of Medical Diagnosis, nine (14.5%) had a Very Low Birth Weight, and four (6.5%) were determined to have a 50% delay in one developmental domain.

First Steps Eligibility



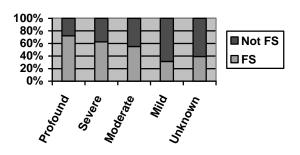
DHSS categorizes children based upon on the degree of their hearing loss: profound, severe, moderate, mild, and unknown. Thirteen of the 18 children (72.2%) in the 'profound' category were found in the First Steps database. Ten of 16 'severe' children (62.5%), 22 of 40 'moderate' children (55.0%), 17 of 54 'mild' children, and 11 of 28 'unknown' children had also been referred to First Steps. Put another way, those with a greater likely need for assistance (those in the 'profound' and 'severe' categories) were over 60% more likely to be found in the First Steps

database than those with a lesser likely need (those

in the 'moderate' and 'mild' categories). Of those in the former category, 67.6% had been involved with First Steps at some point, compared to 41.5% of those in the latter category.

Of the 62 children found eligible for First Steps, all of them were found to have a disease or diagnosis represented by an ICD9² code and description (there were 78 total diagnoses for these 62 children). Thirty-one of these 62 children (50%) had a disease/diagnosis related to

Percentage Referred to First Steps by Degree of Hearing Loss



children (50%) had a disease/diagnosis related to hearing loss. The list of different descriptions are as follows:

- Hearing Loss 19 children
- Unspecified Hearing Loss 5
- Sensorineural Hearing Loss (Specified and Unspecified) 3
- Conductive Hearing Loss (Specified and Unspecified) 2
- Central Hearing Loss 1
- Other Specified Forms of Hearing Loss 1

Broken out by degree of hearing loss, the following is noticed. Ten of the 13 children (76.9%) in the First Steps database with hearing loss described as 'profound' had a hearing-related ICD9 designation. Each step down in degree saw a step down in the percentage of overall children represented with such a designation. Seven of the 10 children (70%) with a 'severe' loss had a hearing-related ICD9; eleven of 22 (50.0%) with a 'moderate' loss were represented; and only two of the 17 'mild' loss children (11.8%) had a hearing-related ICD9 (one child with a hearing-related ICD9 had an "unknown" degree of hearing loss).

² International Classification of Diseases, 9th Ed.

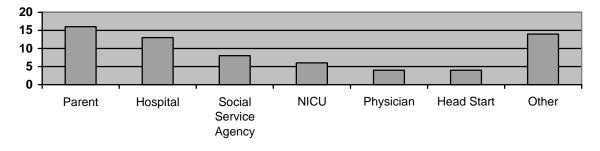
Other ICD9 designations that appeared more than once among the 73 First Steps children from DHSS' list include the following:

Disorders Relating to Other Preterm Infants - 4children

- Down's Syndrome – 4
- Unspecified Delay in Development – 4
- 25-28 completed weeks of gestation 3
- Cleft Palate 3
- Congenital Anomalies of Foot, Skull and Face Bones, or Unspecified 3
- Congenital Hydrocephalus 2
- Disorders Relating to Extreme Immaturity of Infant 2
- Low Birth Weight Status, 1000-1999 grams 2
- Respiratory Distress Syndrome in Newborn 2

A look at the primary referral sources of children with hearing concerns in the First Steps database shows that "Parents" and "Hospital (other than NICU)" are the top two overall referral sources.

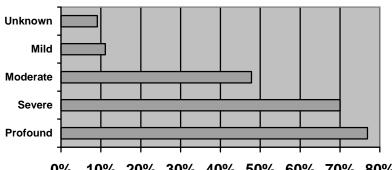
Referral Sources for 2003 Hearing Screening Children Referred to First Steps Program



The full list of referral sources for these children with hearing concerns is as follows:

- Parent 16 children
- Hospital (other than NICU) 13
- Social Service Agency (inc. DFS) 8

First Steps Children with Hearing-Related ICD9s, by Degree of Hearing Loss



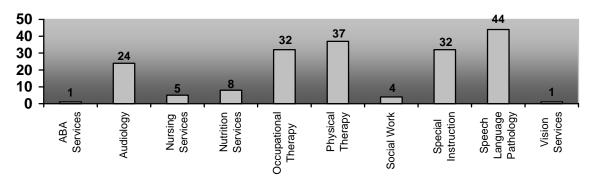
10% 20% 30% 40% 50% 60% 70% 80%

- Neonatal Intensive Care Unit [NICU] 6
- Head Start/Early Head Start 4
- Physician (including Physch.) 4
- Child Care program/provider 3
- MO School for the Deaf [MSD] 3
- Other health care provider 3
- Department of Mental Health [DMH] 2
- Other LEA program 1
- Parents as Teachers 1
- Public Health facilities/providers 1

Early Intervention Services

IDEA and the Missouri State regulations require that Part C funds may only be used for early intervention services that an eligible child needs but is not currently entitled to under any other Federal, State, local or private source. Services and assistive technology reported in this section reflects only those services paid for with Part C funds.

The types of services most provided for the 61 families and children with IFSPs are as follows: forty-four children received Speech Language Pathology services, 37 received Physical Therapy, 32 received Special Instruction, 32 received Occupational Therapy, and 24 received Audiological services. A complete list of services is included in the chart below.



Services Received for the 61 Newborn Hearing Screening List Children who had Received IFSP Services as of August 22, 2004

As of August 22, 2004, 30 children were receiving Speech Language Pathology services (a total of 42 active authorizations) and 16 were receiving Audiology services (a total of 27 active authorizations).³ While all 27 active Audiology authorizations had a Special

³ The number of children receiving active SLP and Audiology services on August 22, 2004 (30 and 16, respectively), is different than the number of children with SLP and Audiology on their IFSP (44 and 24, respectively) because services are authorized for a period that does not necessarily encompass the entire active period of the IFSP. Therefore, children with a given service authorized on their IFSP will receive that service at some point, but possibly might not be receiving it at a given time or date.

Purpose Center setting, the 42 SLP authorizations were provided in a variety of settings. A majority of them were in the Home (30, or 71.4%), but these authorizations also took place in a Special Purpose Center (7, or 16.7%), Other Family Location (4, or 9.5%), and Community Setting (1, or 2.4%).

Amplification and Other Assistive Technologies

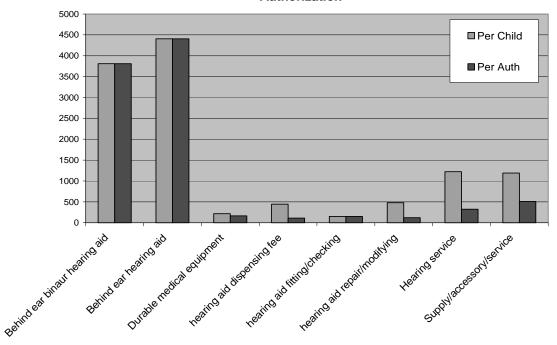
For the year spanning from July 2003 to July 2004, 25 children among the group of 73 involved in First Steps had received some sort of amplification device or other assistive technology through First Steps funding, all between the dates of July 10, 2003, and July 17, 2004. A total of 107 authorizations of assistive technology for these children cost a total of \$81,297.59.

There were eight categories of assistive technology authorizations given to the 25 children mentioned in the previous paragraph. They are presented below, in order of total cost:

- Behind ear hearing aid \$35,250.00
 - o 8 authorizations for 8 children
 - o Average: \$4406 per authorization and per child
- Hearing service \$21,960.95
 - o 68 authorizations for 18 children
 - o Average: \$323 per authorization, \$1220 per child
- Behind ear binaural hearing aid \$15,230.00
 - o 4 authorizations for 4 children
 - o Average: \$3808 per authorization and per child
- Supply/Accessory/Service \$7,133.67
 - o 14 authorizations for 6 children
 - o Average: \$510 per authorization, \$1189 per child
- Durable medical equipment \$648.97
 - o 4 authorizations for 3 children
 - o Average: \$162 per authorization, \$216 per child
- Hearing aid repair/modifying \$480.00
 - o 4 authorizations for 1 child
 - o Average: \$120 per authorization, \$480 per child
- Hearing aid dispensing fee \$444.00
 - o 4 authorizations for 1 child
 - o Average: \$111 per authorization, \$444 per child
- Hearing aid fitting/checking \$150.00
 - o 1 authorization for 1 child
 - o Average: \$150 per authorization and per child

The amount spent per child and per authorization is shown in the following graph.

Amount Spent on Assistive Technologies per First Steps Child and Individual Authorization



Type of Assistive Technology

Follow-up on Children Born and Identified through the NHS Program in 2002

2002 Newborn Hearing Screening List		
145 total children		
62 in First Steps Database		
21 inactivated		
	5 withdrawn	
	3 moved to another SPOE	
	3 unable to contact/locate	
	2 completed IFSP	
	2 deceased	
	2 Part B referral refused by parent	
	1 moved out of state	
	1 ineligible for Pt. B, exited to other	
	program	
	1 ineligible for Pt. C	
	1 reason unknown	
41 still active		
	34 active IFSP	
	7 in referral	

Of the children identified by the Newborn Hearing Screening program in 2002, 45 were in the First Steps database as of the September 2003 report. With more recent referrals taken into account, that number has grown to 62. Of those 62, 41 are still active in the system; twenty-one have been inactivated. In all, 51 have received services from an IFSP at some point. Seven children are listed as "still in referral."

As of August 22, 2004, there were 34 children with active IFSPs in the SPOE Database. Thirty-one of those 34 children were receiving a total of 58 authorizations for Speech Language Pathology; ten children were receiving a total of 14 authorizations for Audiology.

These authorizations were separated into the following settings:

Speech Language Pathology (58 total authorizations)

- Home − 45
- Community Setting 8
- Special Purpose Center 4
- Other Family Setting 1

Audiology (14 total authorizations)

- Special Purpose Center 13
- Home − 1

Fifty-four of the 58 SLP authorizations were to occur in a natural environment (home, community setting, other family setting). Due to the nature of audiology service, it is almost always given at a 'special purpose center' and therefore not in what is deemed a natural environment; that serves to explain why only one of fourteen audiology authorizations was to take place in a natural environment.